



Care and support
through terminal illness



EasyRead version

Caring for someone with an illness they will probably die from

Looking after yourself

Booklet 2



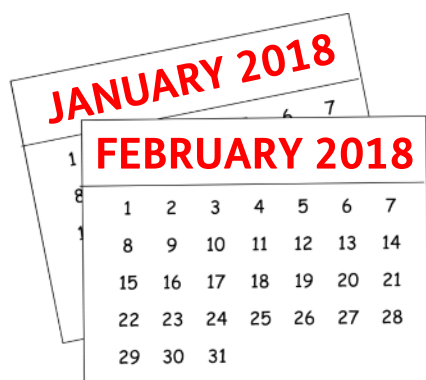
About this booklet



Sometimes people have an illness that cannot be cured and that they will probably die from.



This is often called a **terminal illness**.



Depending on the illness a person has, they might live for days, weeks, months or even years.



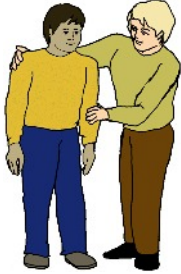
Care and support
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Marie Curie is a charity. We have written this EasyRead booklet to help you think about looking after yourself if you are caring for someone with a an illness they will probably die from.

This booklet talks about:



- your feelings 3



- coping with other people's feelings 7



- talking to children 12



- taking a break 15



- how we can help 28



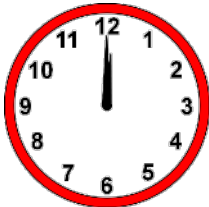
- how you can help us 32

Your feelings



A **carer** is someone who looks after a friend or family member who cannot do everything they need for themselves.

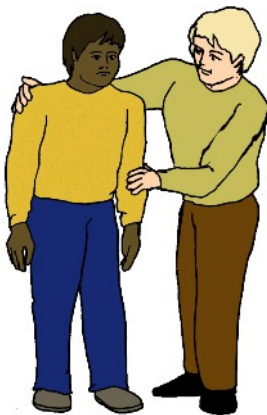
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You might care for someone all the time or for just a few hours a week.



Being a carer can be stressful. It can be difficult to find time to do things you like, such as meeting up with friends or going out. This can make you feel very alone.



But it is important to look after yourself and get support if you need it.



Feeling angry or guilty

It is normal to feel angry sometimes about what is happening and the way things have changed.



It is also normal to feel guilty or sad.



Many people feel this way.



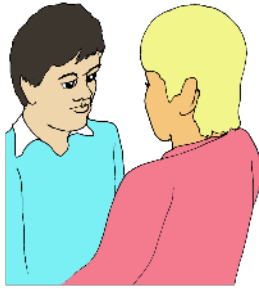
Hiding your feelings can make you feel worse. This could also make it harder for you to care for the person who is ill.



Things might feel too big to think about or deal with.



It might help if you talk to friends or family about it.



Or you might want to talk to someone who is going through the same thing.



Carers UK and Carers Trust are charities that can help you speak to other people who are carers too.



Visit **www.carers.org** and **www.carersuk.org** to find out more information. These websites are not in EasyRead.



You might feel more comfortable talking about your feelings with someone you don't know.



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Marie Curie may be able to help. Call our Support Line for free on **0800 090 2309**.



If your feelings become a big problem for you, you can talk to your doctor (GP).



They may be able to help you talk to a **counsellor**.



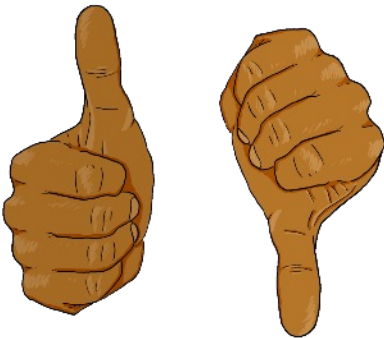
Counsellors are specially trained to help you talk about your feelings.

Coping with other people's feelings

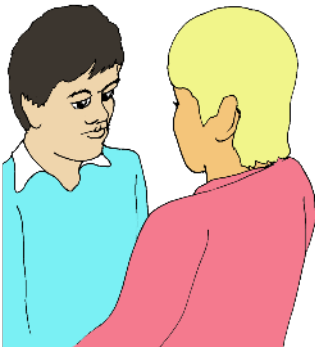


The person you are caring for

People who have an illness they will probably die from might have lots of strong feelings about it.



They will have good days and bad days.



Sometimes they might not want to talk about their illness. At other times they might want to talk about it a lot which might upset you.



They might act differently to how they normally are. For example, they might be:

- angry because they are losing control



- confused



- sad



- scared.



This might affect how you get on together.



Try to get the person to do as much as they can for themselves and make as many choices as possible, if that's what they want.



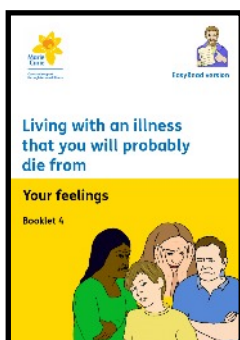
If their feelings become a big problem, they could talk to someone else who is ill or a **counsellor**.



Their doctor (GP) or nurse can help you get in touch with a **counsellor**.



The person you are caring for can find out more about coping with their feelings by reading information on our website at **www.mariecurie.org.uk/help**



We have also written an EasyRead booklet about it that they can read, called ‘Living with an illness that you will probably die from: Your feelings’.

Friends and other people in your family



Friends, or other people from your family, will probably want to talk to you about the person you are caring for. They might want to:



- find out how they're doing



- ask questions about their illness



- share their feelings.



Your friends or other people from your family might feel frightened, upset or angry. It can be difficult if they do not understand how ill the person is.



You might find it helpful to ask one or two family members or friends to tell everyone else about what is happening, so you don't have to. This can make things easier for you.



Remember that you are not responsible for other people's feelings and that they need to look after themselves.



You could tell them to call the Marie Curie Support Line or visit our website to get more support.

Talking to children



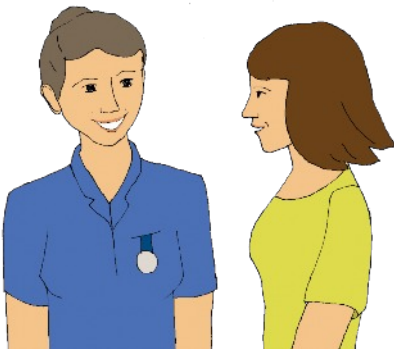
It is best to tell children what is happening as soon as possible.



Choose a place where they feel comfortable. This could be their bedroom or another place in their house where they like to spend time.



Involve the person who is ill if they want to be there.



If you're not sure what to say, you can ask a nurse or someone else involved in the person's care for help. You can also ask them to be there when you talk to the child.



It is important to be honest with children and tell them as much as they can understand.



You could start by telling the child what the doctors have told you and then add other information if they want it.



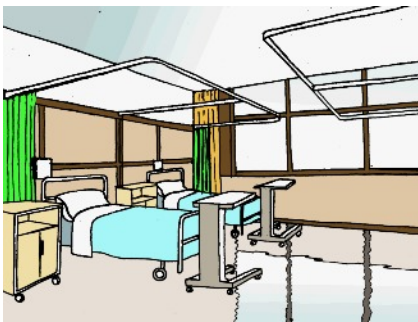
If you do not know the answer to a question they ask, it's OK to tell them you don't know.



If the person who is ill is the child's parent, you could tell their teacher. This will help them support the child at school.



If you are telling someone else's child that someone they know is going to die, it is good to have their parents with them. You could ask the child's parents to tell them.



If you are taking a child to hospital to see the person who is ill, it's good to tell the child what they will look like and what to expect.



If the child does not want to visit, they could draw a picture or make a card for the person who is ill.

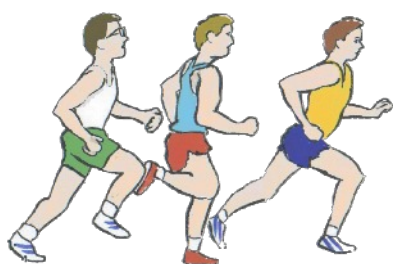
Taking a break



Being a carer can make you very tired and upset so it is important to look after yourself by:



- eating well



- getting some exercise so you feel more happy and healthy



- getting enough sleep.



You might need to ask someone to sit with the person you care for so you can take a break and do these things.



If you think caring is making you poorly, it is important to talk to someone about it. You could speak to your doctor or call our Support Line on **0800 090 2309**.

Complementary therapies

These are treatments that may help you to relax or sleep better. They include things like:



- massage



- yoga



- art therapy.



Your nurse or doctor (GP) can tell you if these are free on the NHS for carers.



Your local hospice or support group might offer some therapies for free or for cheaper.



A **hospice** is a place that cares for people who have an illness they may die from. It can support you too.



The **Complementary and Natural Healthcare Council** has a list of therapists you pay for on their website: www.cnhc.org.uk. This website is not EasyRead.



Always ask how much it will cost before you see a complementary therapist.

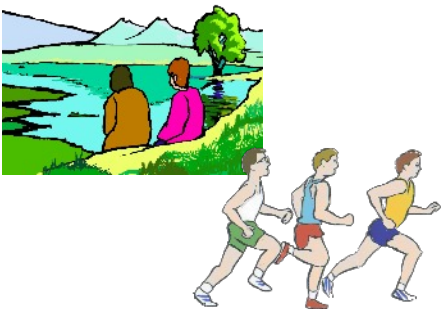
Taking time out



It is important to have some time to yourself to help you stay healthy. If you cannot leave the person you are caring for, you can get **respite care** to give you a break.



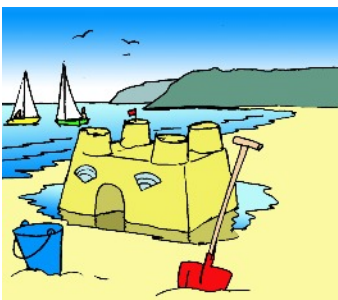
Respite means someone else cares for the person who is ill at home, in a care home or a hospice so you can:



- have a short break to do a hobby or exercise or meet friends



- get some sleep



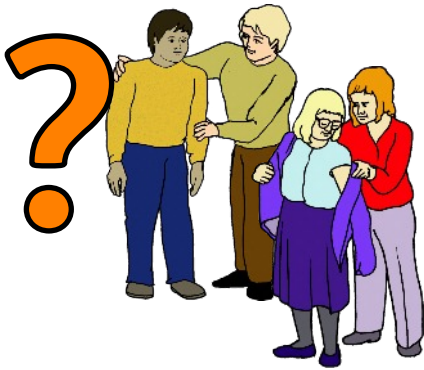
- go on holiday.



Sometimes your family and friends can help.



If not, your local council can do an **assessment** to see what support you need.



This means looking at the things both you and the person you care for need help with. Your local council will then decide if you can get support.



If the council gives you respite care you might have to pay for it.



Charities like Carers UK, Carers Trust or your local carers group can tell you more about respite care. Their websites are: **www.carersuk.org** and **www.carers.org**. These websites are not EasyRead.

Getting ready for the end of the person's life



It can take time for the person you are caring for to understand and believe that they have an illness that they will probably die from.



When they do, it might help the person you care for feel calmer and more in control.



This can help you plan together. It can also help you and the person you care for prepare for their death.



The most important thing is for the person to have the care they want, in the place they choose. This could be in their home or in a hospice.



You might find it helpful to talk to someone during this time.



You may like to talk to family members or friends.



You might want to talk to a religious leader about your beliefs and faith. They can also talk to the person who is dying.



They will talk to you even if you do not have religious beliefs. They can support you before and after the person you care for has died.



Your hospital or hospice can tell you how to contact a religious leader.



You could also talk to a counsellor who can help you if you are feeling sad, worried or finding it hard to face up to things.



They can talk to you about your feelings.



You can also contact the Marie Curie Support Line on **0800 090 2309**.

When you stop being the person's carer



Your feelings

Your life will change when you stop caring for the person. There will be lots of things you will not do anymore.



These changes can be hard. You might feel that you do not have anything important to do now.



Or you might feel relieved. Caring for someone is difficult, so don't feel guilty if this is how you feel.



You might also feel proud that you were able to help someone who is special to you at the end of their life.



All these feelings are normal so try not to worry and don't be too hard on yourself.



Changes in your life

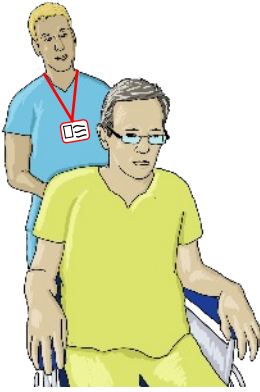
While you were busy caring you probably did not spend much time with your friends.



You will have spent a lot of time with doctors and nurses and might miss them now.



You might want to carry on seeing the doctors and nurses that helped look after your friend or family member.



You could do this by going back to the hospital or hospice as a volunteer. But it may be better to wait for a while, as it could upset you.



It might also help to join Marie Curie's Expert Voices Group. This is a group of people who have experience of caring for someone who had an illness they died from.



The Expert Voices Group helps us with our charity work. If you want to know how to get involved please ring us on **0800 090 2309**.



You might want to start doing things you did before you were a carer. Or you might want to try something new.



This can be good for you. But don't rush into things if you do not feel ready. Take your time.



Volunteering is a good way to meet new people. There is information about volunteering on our website: **mariecurie.org.uk/get-involved** and on the Do-it website: **do-it.org**.



Support

You may be very sad and upset that the person you cared for has died.



It might help to talk to someone like a counsellor about your feelings.



If you don't want to talk to someone face to face, there are telephone helplines you can call:



Cruse Bereavement Care
0808 808 1677



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Marie Curie Support Line
0800 090 2309



Bereavement Advice Centre
0800 634 9494



Your Marie Curie Nurse can tell you about support to help you cope with your feelings. They can also tell you about services that can help.

How we can help

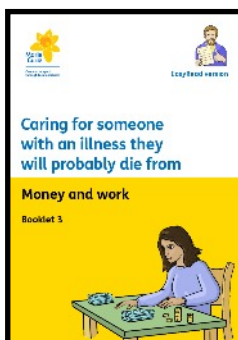


There are lots of different ways we can answer questions or support you and the person you are caring for.

We have 2 other booklets about caring for someone with an illness that they will probably die from.

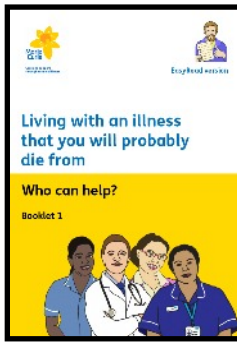


1. Who can help?

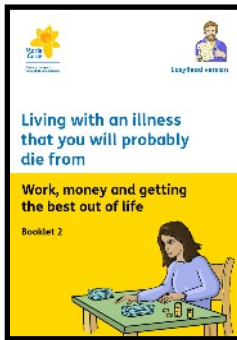


3. Money and work

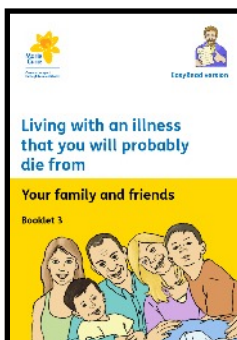
We have 5 booklets about living with an illness you will probably die from.



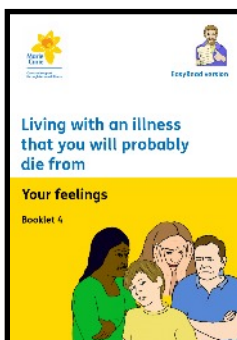
1. Who can help?



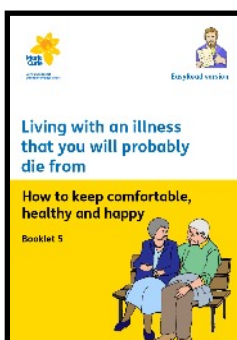
2. Work, money and getting the best out of life



3. Your family and friends



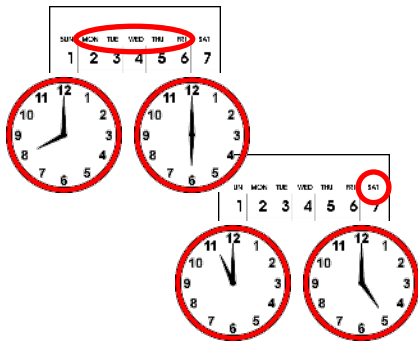
4. Your feelings



5. How to keep comfortable, healthy and happy.



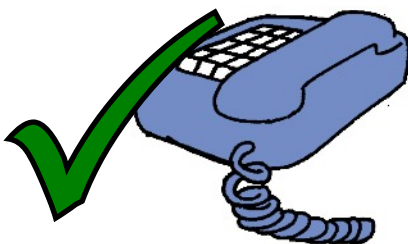
You, the person you are caring for or your family and friends can phone us to talk about what is happening and how you are feeling. You can call our Support Line on **0800 090 2309**.



It is open 8am – 6pm Monday to Friday and 11am to 5pm on Saturdays.

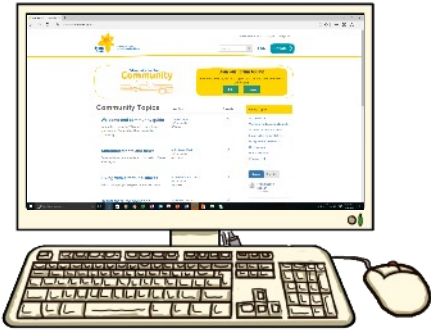


There is also information on our website: **mariecurie.org.uk/help**



The information on our website is not EasyRead but if you call us we can explain things to you.

Marie Curie Community



Share ideas or talk to other people who are caring for someone with an illness that cannot be cured:

community.mariecurie.org.uk
24 hours a day



Marie Curie Nurses

If the person wants to stay in their own home when they are dying our nurses can care for them:

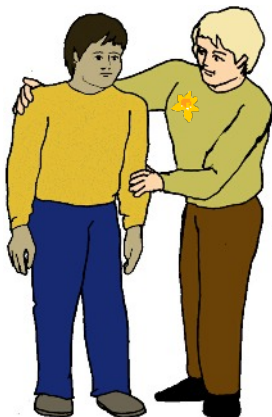
www.mariecurie.org.uk/nurses



Marie Curie Hospices

A hospice is a place that cares for people who have an illness they will probably die from and can support you too:

www.mariecurie.org.uk/hospices



Marie Curie Helper

Our trained volunteers can visit the person for a chat or take them to appointments at their doctors' surgery or hospital:

www.mariecurie.org.uk/helper

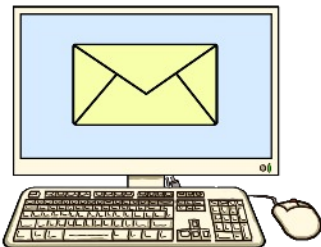
How you can help us



Please tell us what you think about this booklet.



It will help us to write better information for people who are caring for someone with an illness they will probably die from.



You can email us at:
review@mariecurie.org.uk



or call our Support Line on:
0800 090 2309.

Credits



Care and support
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This is an EasyRead booklet about caring for someone with an illness they will probably die from.

It was written by the charity Marie Curie.

It uses easy words and pictures to make the information easy to understand.



It meets the European EasyRead Standard.



Leading **Lives**
Your life / Our support

It has been user-checked by the **Making It Easier Group** of people with learning disabilities.



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www.inspired.pics

Marie Curie – why we're here

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.



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